AMERICAN
PSYCHOLOGICAL
ASSOCIATION

Practice Directorate

June 13, 2003

Jo Anne B. Barnhart
Commissioner of Social Security
P.O. Box 17703
Baltimore, MD 21235-7703

Re: Advance notice of proposed rulemaking on revised medical criteria for evaluating mental disorders (68 FR 12639, March 17, 2003)

Dear Commissioner Barnhart:

I am writing on behalf of the American Psychological Association (APA), the professional organization representing more than 150,000 members and affiliates engaged in the practice, research and teaching of psychology. APA wishes to submit comments in response to the advance notice of proposed rulemaking on revised medical criteria for evaluating mental disorders published in the *Federal Register* on March 17, 2003.

In the notice, the Social Security Administration (SSA) specifically requests comments on the recommendations in the 2002 National Research Council (NRC) report, the report by Schroeder et. al. Regarding usage of the term "mental retardation", and the classification of mental retardation by the American Association on Mental Retardation (AAMR). We wish to address each of these categories as follows:

The National Research Council Report (2002). The NRC panel produced findings in the form of recommendations for changes in SSA procedures related to identification of an individual as meeting the SSA mental retardation impairment listing criteria, and with respect to the use of established assessment methods related to mental retardation diagnosis and classification rather than generic functional criteria, e.g., adaptive behavior measures.

Mental retardation differs from other developmental disorders and from mental disorders generally in terms of diagnostic process, because its diagnosis has a primarily psychometric basis. As noted by the NRC panel, one of the important issues faced by SSA disability determination specialists when an application for services due to mental retardation is received, the information provided to verify functional limitations related to employability or projected vocational performance is often inadequate. In order to address this core concern, the NRC panel recommended that functional limitations associated with intellectual impairment be assessed both clinically and

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psychometrically. Accordingly, the functional criteria applied to eligibility determination for individuals with mental retardation should conform to those that can be derived in substantial part from the structure of existing, well-normed and extensive, adaptive behavior measures, rather than derived from criteria that are applied uniformly across mental retardation or other developmental disabilities, and other, quite different, mental disorders in sections 12.00 and 112.00. These recommendations are presented on pages 205-207 and 242-244 of the NRC report, and APA strongly recommends that SSA adopt the recommendations in practice, and where appropriate, in the regulations.

The panel also made recommendations regarding high quality practice of intellectual assessment and ascertainment of developmental onset (as manifested inconsistently for some, during the developmental period) as they relate to determinations of eligibility due to mental retardation. These recommendations are presented on pages 139-140 and 280-281 of the NRC report. Again, APA strongly recommends that SSA adopt these recommendations in practice, and where appropriate, in the regulations. These recommended changes, and those above could valuably be included in sections 404.1520a and 416.920a in order to promote acceptable and appropriate practice by clinicians conducting assessments for the purposes of meeting requirements for application to SSA.

Schroeder et al. 2002. We concur with the conclusions of Schroeder et al. in that although the term "mental retardation" is disliked or disavowed by members of the disability advocacy community, practitioners and researchers alike are confronted by the fact that (1) there is no consensus regarding a different term that could supercede "mental retardation", and (2) it is likely that any surrogate term would rapidly acquire the same negative connotations as mental retardation, and therefore would not effectively mitigate any stigma associated with professional or governmental use of the term.

Alternative terms, such as developmental disability, or intellectual disability, even cognitive disability, are generally very broad in their meaning. While these terms clearly would include mental retardation, fail to clearly distinguish mental retardation from other disabilities. For example, Alzheimer's disease is both a cognitive disability and an intellectual disability, as are other dementias or multiple severe learning disabilities. The term "developmental disabilities" refers to a range of neurodevelopmental disorders including mental retardation but also autism, cerebral palsy, epilepsy, and developmental onset neurologic injuries. These other disabilities vary differently in their range and scope of impact on functioning, and characteristic impacts on employment opportunities, for people who are affected by them; thus they should be determined separately from one another within SSI and SSDI programs.

Retention of the term mental retardation, as generally understood based on DSM-IV-TR or on the 1996 definition contained in a publication by APA Division 33 (Mental Retardation and Developmental Disabilities)[1] permits SSA to continue to address the needs of a specific population segment. This is defined by longstanding professional

[1] J.W. Jacobson & J.A. Mulick (Eds.), Manual of diagnosis and professional practice in mental retardation (pp. 13-53). Washington, DC: American Psychological Association

practice that may not be as varied in classification as might be implied by the existence of alternative manualized definitions. APA thus recommends that SSA continue to define mental retardation in consonance with the essential characteristics of the DSM model, simplified with blending of elements of the 1996 APA definition in description of functional limitations.

AAMR (2002). We recommend that content in AAMR (2002) be considered in the context of research indicating, for example, that levels or degrees of mental retardation should be recognized as manifesting predictive validity for developmental and social outcomes for individuals with mental retardation. AAMR (2002) perpetuates the practice, dating back to a 1992 manual by AAMR, of eliminating levels or degrees of mental retardation, and in doing so vitiates one characterization of degree of disability associated with a diagnosis of mental retardation, and that has permitted ready description of participants in research studies allowing readers and other researchers to understand salient characteristics of participants that may in some cases affect outcomes or findings (i.e., to consider whether the participants in two studies were similar or quite different with respect to degree of intellectual and adaptive functioning). A definitive source on research related to classification on the basis of intellectual and adaptive functioning can be found in the 1996 APA Division 33 publication.

In its 2002 manual, AAMR adopted a research-based framework for adaptive behavior assessment and characterization. Unfortunately, contemporary adaptive behavior assessment instruments generally have structures that differ from this framework, and so do not psychometrically assess all relevant aspects of functioning described in general terms by AAMR. Further, although the AAMR (2002) model of adaptive behavior spans a wide range of conceptual, social, and practical aspects of functioning, it does so at the sacrifice of depth and specificity and only provides slight guidance to practicing clinicians on assessment of key foundational skills or skills that are more specifically pertinent to potential vocational performance (e.g., workplace-determined specific skills, social skills). For these reasons, APA recommends that the recommendations of the NRC panel with respect to the proper ascertainment and appraisal of adaptive behavior limitations be adopted in guidance materials and guidance elements of the regulations. The recommendations should also be broadly communicated to practitioners through any educational activities related to changes in the impairment listings generally, and in the regulations as appropriate (i.e., sections 12.00 and 112.00 and more generally in 20 CFR sections 404.1520a and 416.920a).

We thank you for the opportunity to comment on these issues concerning the evaluation of mental disorders and offer our assistance to SSA on any future efforts to revise the regulations. For more information please contact me at 202-336-5889.

Sincerely,

Diane M. Pedulla, J.D.
Director of Regulatory Affairs